

Marie Curie Consultation Response

Excess Deaths since the start of the Pandemic Inquiry- Scottish Parliament Covid-19 Recovery Committee

Marie Curie supports the Covid-19 Recovery Committee's inquiry into excess deaths since the start of the pandemic. There has been a notable shift from hospital to community deaths throughout the pandemic, resulting in a significant number of excess deaths at home. This inquiry should support the identification of key trends with a focus on health outcomes of patients, including terminally ill people, and identification of lessons and recommendations.

During the pandemic Marie Curie provided care and support to more terminally ill and dying people in Scotland than ever before:

- **We supported over 9,000 people**, as well as their families and carers
- Last year around **100,000 people used our Information and Support services in Scotland**, which provided up-to-date information, support and guidance to families and professionals on all aspects of dying, death and bereavement, as well as ever changing information around Covid-19
- We **continued to deliver frontline health and palliative care services** to families across Scotland throughout the pandemic where **we faced considerable pressures** on our finances, workforce and services

Our response below is based on our expert knowledge and experience of delivering community-based palliative care services during the pandemic.

Q: Has the public health emergency shifted from COVID-19 deaths to deaths from non-COVID-19 conditions?

Q: What accounts for the deaths from non-COVID-19 conditions?

****the response to the above two questions has been combined below.***

Throughout the Covid-19 pandemic in Scotland the number of people dying of a terminal illness, such as heart failure, dementia, cancer and many other conditions continued as it has done in every other year with over 50,000 deaths in 2020-21.

Although the majority of these deaths were to be expected, the circumstances in which people died were very different to pre-pandemic.

In particular, **there has been a 40% increase in the number of people dying at home with a terminal condition and a similar drop in such deaths in hospital**. There have been more than 6,000 excess deaths at home during the pandemic, the majority of which were from cancer, dementia and heart disease¹. Over 24,000 people died at home in 2020/21.

This has put huge pressure on primary and social care, as well as community palliative care services, but mostly on family and friends who have undoubtedly had to carry out the bulk of the care for their dying loved ones, and likely without the physical, emotional and financial support and care they needed to be a carer.

We understand from the experience of those that used our services during this period that some of this care at home was only possible as a result of Furlough or working from home,

¹ National Records of Scotland

which allowed families the capacity and flexibility to be able to care for loved ones. It is not clear how much this influenced this overall shift in trend, or what will happen to the trend when more people are required to work from their place of work again, rather than at home.

The trend of increased deaths at home has continued even as waves of Covid-19 have dropped and hospital numbers have fallen. This suggests that this trend might continue into the short and medium term. Over the last ten years there has been a steady increase in home deaths, and prior to Covid-19 this had expected to continue, but the pandemic has accelerated it considerably.

This trend raises key questions that must be answered:

- Why have more people been able to die at home than before?
- What kind of support has been available to people dying at home, as well as their carers?
- Should we work to maintain this trend and if so, how can this be achieved?

It will be vital to understand the care people dying of a terminal illness at home received, as well as the support any family carers received, during that time to inform this inquiry and its subsequent recommendations.

The valuable lessons and gaps that could be identified would support future service delivery and design for both patients and carers, especially as this trend of high levels of home deaths is set to continue beyond the pandemic.

Data from a range of community-based service providers including primary care services, care at home services, as well as palliative care services including third sector providers and independent hospices should be at the core of this approach.

Q: Is there evidence that patients are now presenting in a more acute condition?

Many people were unable to access diagnostic services, treatment or ignored symptoms during the pandemic, particularly during the earlier waves. This has had an impact of people being diagnosed much later in their disease trajectory and as a result some have been considered palliative rather than curative.

In 2020-21, Marie Curie saw its highest number of patients on record in Scotland, driven by an almost 15% increase in demand for our nursing services in the community. However, we still could not meet all of the demand and we have also seen terminally ill people accessing services much later than we would have done previously and much closer to the end of their lives. As a result, their needs have been greater, more complex and outcomes far less satisfactory than should be expected; this has also been true of their carers.

Case Study

Throughout the pandemic, our Marie Curie nursing services have been particularly affected by increased of deaths in the community, particularly in Glasgow, due to Covid-19 prevalence in this region. Trends emerged of high numbers of late patient referrals from District Nurses caused by families not engaging with services until breaking point due to fears of Covid-19 infection, or increased family support from either working at home full time or people on furlough.

This meant a large proportion of the terminally ill patients we cared for at home through our Fast Track, Rapid Response and Managed Care services were at the end of their lives with a prognosis of just a few days. Our Fast Track service teams have regularly experienced multiple deaths of patients over very short periods of time.

We strongly believe the incidents and prevalence of people accessing health and social care services much later than would have been expected prior to the pandemic, and what impact this had on their outcomes, should be a vital exploratory aspect of this inquiry.

How this might be prevented in the future when extreme pressures are exerted on the health and social care system should also be central to the committee's considerations and recommendations.

The potential impact on palliative care services from possible increase in those living with a terminal illness and approaching the end of life as a result of delayed access to treatment or non-presentation with symptoms as a result of the pandemic should also be a vital consideration of the inquiry.

Q: Is there enough strategic focus on the indirect health impacts of the pandemic?

Q: What are the realistic options open to Government in addressing the indirect health impact of the virus this winter?

***the responses to the above two questions have been combined below*

As we have seen during the pandemic, there has been over 6,000 excess deaths at home; the majority of which have been from cancer, heart failure and dementia².

It is vital that the indirect impact of Covid-19 on the wider health and social care system, including the care of those dying from terminal conditions from both the perspectives of the patient and family carers providing support at home, is given the strategic focus it deserves.

Marie Curie believes the Scottish Government's NHS Recovery Plan published in 2021, which is largely focused on curative treatments, mental health services, primary care and staff wellbeing – all of which are extremely important – has been a missed opportunity to look at improving the support for the increasing numbers of terminally ill people dying in the community particularly at home, from hospital as a result of the pandemic, and what this means in terms of the need for increased support in the community, but also the freeing up of acute capacity.

The trend of increased deaths in community settings is set to continue long after the pandemic, as Scotland's ageing population means more people will be dying in the coming years, with annual deaths expected to be over 65,000 per year by 2040. [Marie Curie research](#) (undertaken before Covid-19) found that by 2040:

- 62,000+ people will be dying with palliative care needs (10,000 more per year than currently)
- Dying with at least one terminal condition (co-morbidities) will have increased by 80%
- The greatest increase in palliative care need will be in over 85s
- **Two thirds of all deaths will be happening in community settings; including in people's own homes, care homes and hospices)**

During Covid-19, we have gained insight into what increased demand for palliative support in the community could look like. But it is unknown whether those terminally ill people, their families and carers were able to access and receive the care and support they needed during this time due to community services being so stretched.

² National Records of Scotland

Community services and workforces must be equipped and feel empowered to be able to deliver palliative and end of life care, both in the short and longer term, which we believe should be a focus of the committee's inquiry.

As in other health and social care settings and services, inequities and inequalities impact on whether or not someone might receive the palliative and end of life support they need. Deprivation, geography, gender, religion, ethnicity, sexuality, learning disability, diagnosis and age are all biological and social determinants that can have an impact on whether someone gets the care and support they need.

Many of these inequities have been exacerbated during the pandemic and could have led to considerably worse outcomes for patients, including poor quality of care and experience at the end of life.

We believe the disproportionate affect Covid-19 has had on seldom heard groups should also be considered as an indirect health impact of the pandemic. This should not be limited to those that experienced a Covid-19 diagnosis, but should look at the wider impact Covid-19 had on other areas of health and social care, including for those living with a terminal illness and approaching the end of life.

We believe the scope of the inquiry must also look further beyond just a short-term focus of addressing indirect impacts of Covid-19. There have been a significant number of excess deaths during the pandemic from a large shift into community settings from hospital.

This raises longer-term questions about:

- The palliative care support terminally ill people and family carers have access to and receive in community settings
- Empowering workforces with the skills and knowledge to confidently deliver palliative and end of life care in all care settings

The pandemic also saw health and social care staff exposed to considerable levels of dying, death and bereavement. For many it was at levels they had never experienced before. Staff were put in positions where often they were the last person a dying person would see providing comfort and support to them.

This has had a serious impact on the health and social care workforce, with many dealing with much higher levels of grief, with added complexity, as a direct result of the pandemic.

Although the Scottish Government made efforts to support workforces dealing with bereavement, which was welcome, there are significant questions remaining around to what extent the workforce received the support it needed and the long term impact this experience has had on them, in addition to what support may be needed in future.

About Marie Curie

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our volunteer led services.

We also provide nationwide support through our information and support service including our national helpline. Marie Curie is also the biggest charitable funder of palliative care research in the UK. In 2020/21, we provided care for over 9,000 people living with a terminal illness, as well as their families and carers across Scotland; our highest ever since the charity was established over 70 years ago.

Our vision is for a better life for people living with a terminal illness, their families and carers. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

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